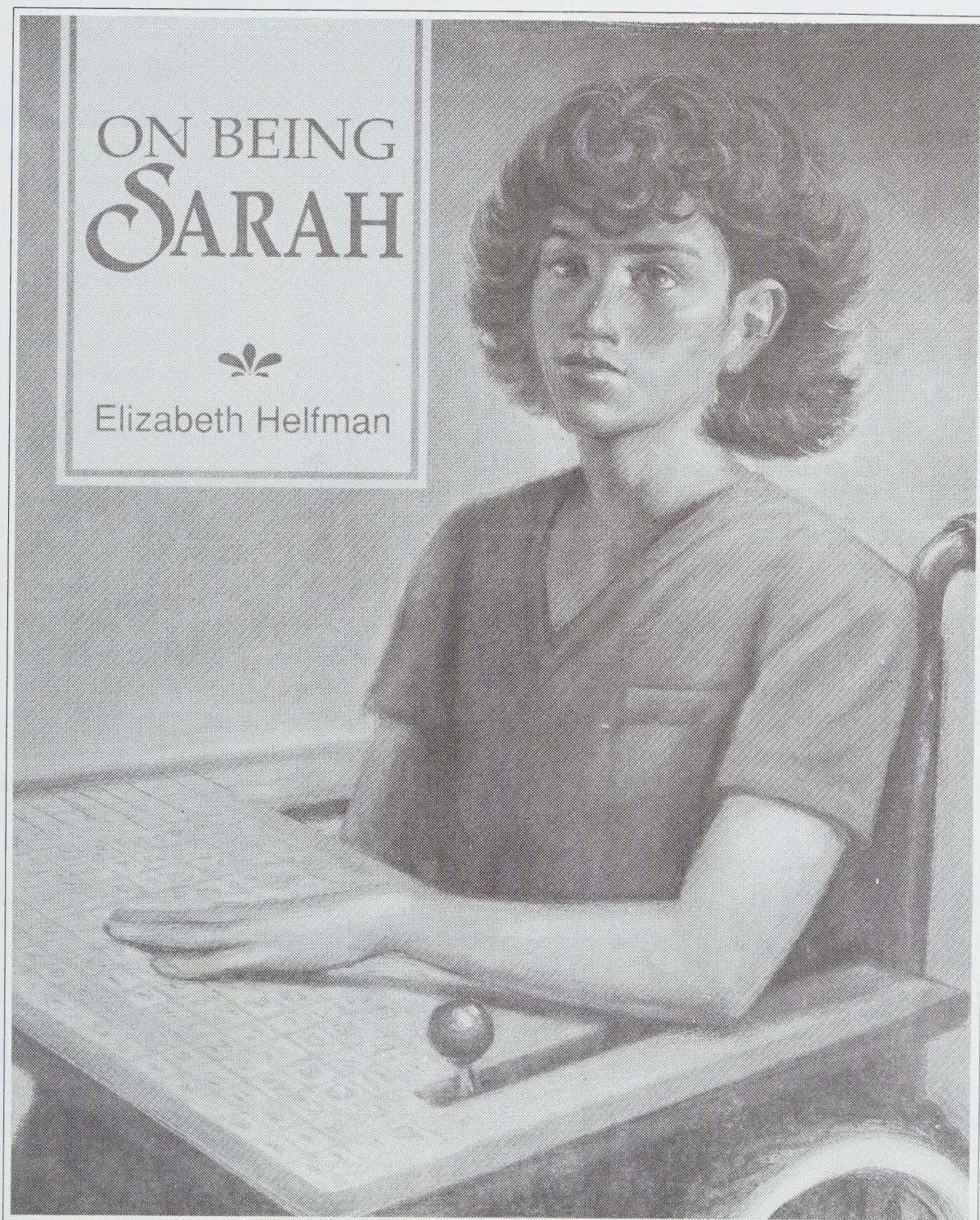


COMMUNICATING TOGETHER

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A QUARTERLY MAGAZINE ABOUT AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

COMMUNICATING TOGETHER VOL. 11, NO. 1/MARCH 1993



PETER LINDSAY
SHIRLEY MCNAUGHTON

One of our strongest aspirations for **Communicating Together** is that we can raise the awareness of issues relating to the life situations of augmentative communicators and provide a forum for exchanging ideas about these issues. Those who are involved in publishing will know how difficult it can be to receive those *Letters to the Editor* and articles that really tell you how your readers are reacting. We were very pleased to receive three carefully considered letters and two immediate responses to our invitation for articles after the December issue. (See *Readers Write, Perspective* and *SymbolTalk*.) Our theme for this issue has become "Reader's Responses".

Since the publication of the December issue, we have had several lively discussions with concerned clinicians trying to decide what stand they should take regarding Facilitated Communication. They want to know if the research is sufficiently conclusive one way or the other to make a decision on its use at this time. They want to know how to balance what appears to be conflicting results in the research and the clinical reports. Is it true that Facilitated Communication may still be appropriate for some individuals regardless of the research results? Can research ever conclusively rule out a clinical approach no matter how carefully the research is conducted? We think not. We hope however, through **Communicating Together**, to provide a dialogue between the two communities.

In our discussions regarding language, we are discovering just how many meanings we attribute to the term. We hope there will be further

comments stimulated by the two articles appearing in *SymbolTalk* this issue. There is certainly much more to be said! The insert being included with **Communicating Together** offers each reader a way of thinking about language with regard to the augmentative communicator he or she knows. We invite your ideas about language development and we look forward to further responses regarding Facilitated Communication. Two further viewpoints regarding language have already been promised, and Rosemary Crossley has sent us an article relating to literacy and FC that we look forward to printing in the June issue. We had hoped to include it in the March issue, but we just had too much copy! One of the letters to the editor suggests that we have an ongoing section relating to Facilitated Communication. If the current interest and challenges continue, we'll be glad to oblige!

We invite your suggestions for other topics and themes. Send them to any of the Associate Editors of **Communicating Together**. We are having our annual planning meeting March 27/28 so your ideas would have our immediate attention.

Within the AAC Family

The AAC community has always felt like a family to those of us who have been involved since the early years. When one of our members suffers a loss, we all share the sadness. During the past year our thoughts have been often with Sarah Blackstone, editor of *Augmentative Communication News* and contributor in many ways to the AAC field. For many months, she and her husband, Gary Pooch, have been waging, together, his battle against cancer. When he "had to go" many of us who have

known Sarah over the years felt deeply her great loss. Yet know that the joy and love they had experienced as partners would always be celebrated by Sarah in the years ahead. We will remember Gary and their happiness together with great fondness; we look forward to many times of sharing with Sarah.

A New Newsletter

We would like to announce to **Communicating Together** readers the publishing of a newsletter, *The Power of Speech*, by the Talformaga Foundation, a not-for-profit corporation directed by Cindy J. Axley, teacher, Leslie Baker, teacher and educational consultant, and Louis Baker, attorney with a practice in disability and special education law and Board of Education member. Leslie and Lou wrote an article about the educating of their son, Nicholas, for **Communicating Together** in June, 1992. Now they are sharing their educational ideas and their expertise through the Talformaga Foundation. The last sentence in their first issue of *The Power of Speech* expresses well their position. They urge advocacy "so that at the end of the school year you can honestly say that if the child accomplishes a lot, you are proud to have helped; if the child accomplishes a little, you did not stand in their way." For further information write the Editor at 127 Central Park Ave., Wilmette, IL 60091, U.S.A.

Sorry we are late

Lastly, we ask you to bear with us as you wait for your copies of the new **Sharing to Learn** publications. We appreciate the orders and are busily trying to get them to you. We hope you will have them within the next month.

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On Being Sarah

ELZABETH HELFMAN



Photograph by Burlington County Times staff photographer, Rose Shields.

Many individuals have had their lives dramatically changed as a result of their experiences with augmentative communication. Elizabeth Helfman, an author of children's stories is a unique example. In this short article she tells us how she came to join the AAC family.

How does an author of books for children and young adults, concerned with written and spoken words, get to write a children's novel about a twelve-year-old girl who can neither walk nor speak intelligibly? Most of my books had been non-fiction, dealing mainly with such subjects as the conservation of natural resources and the meaning to people of the natural world. But one book, *Signs and Symbols Around the World*, published in 1967, was to make a big difference in my life.

Unknown to me, at that time Shirley McNaughton and other teachers in Toronto were looking for some way, any way, to open the world to cerebral palsied children who could not speak intelligibly. Graphic signs might help, if the

children could point to them, but inventing them seemed terribly difficult. Then, in 1971, Shirley discovered my *Signs and Symbols Around the World* in a Toronto library. This book was about the use of graphic signs throughout history, as a means of communication, in various fields of activity. Eight pages were devoted to a symbol system then called Semantography (now known as Blissymbolics), invented by Charles Bliss of Australia for communication across language barriers. There Shirley found symbols for man, woman, child, love, joy, sadness, and many others, all so clear and easy to use. Surely, she thought, this is just what the children need.

Mr. Bliss flew over the ocean to Canada to help, soon after he was contacted about the plan to use his symbols. I did not visit Toronto until mid-winter, 1977.

The original group of symbol users back in 1971 in the Ontario Crippled Children's Centre school included Kari Harrington, who was to become important to me as a friend and later as a real helper when

I was writing *On Being Sarah*. By the time I went to Toronto, Kari had switched to a special class in her neighborhood school in Markham.

However, I did visit the school at OCCC. In Nancy Lageer's classroom I saw children using symbols to communicate with each other and with their helpers. Andrew Murphy and I had a hilarious time trying to understand each other. Ann Running got her ideas across by eye pointing. This is marvelous, I thought. I must write another book about nonspeaking people who find a way of reaching out to the world.

I had of course met Shirley McNaughton; she was to be an invaluable help to me. As time went on there were many visits, interviews, friendships. Always I was welcomed to Toronto as one of those who started the whole movement for using Blissymbols with nonspeaking people. I was not sure I deserved this; after all, I had had no such idea when I wrote my book about signs and symbols. Shirley, especially, included me in many activities. She took me to see Sue Odell and together we visited Kari Harrington and her mother, Ruth. One evening Ruth took me to Kari's school, as she and other parents met with Gwen Mann, Kari's remarkable teacher.

Seeing any child at home is of course quite different from observing the same child in school. Kari at home, in her wheelchair, was a spunky and interesting twelve-year-old. And I could see that having a loving and devoted mother had much to do with this.

So much had been happening for the original "symbol children" and others — movies, trips, many kinds

of learning. I took in as much as I could. There were other visits with Kari. *Blissymbolics: Speaking Without Speech* was published in 1981. It was not only about Blissymbolics but to some extent about other methods, with emphasis always on the children, and sometimes adults, who had found new ways of speaking. There was a whole chapter about Kari; I still have a copy of the autobiography she wrote in her early teens.

At home in Connecticut, I had weekly symbol conversations with two nonspeaking women in a nearby institution, and I put them in the book, too. *Blissymbolics: Speaking Without Speech* won a Golden Kite nonfiction award from the Society of Children's Book Writers and was a selection of the Young Adult Literary Guild.

I then turned to fiction. I wanted to write a book that would help children to feel what it would be like to live without any possibility of ever walking on two legs or being able to talk as other people do. I wanted to show, too, that such a life, with the help of loving family and friends, can be full of interest and hope for the future. And I tried to make this a good story.

The child in my book, twelve years old, is called Sarah; while I was writing it I felt I *was* Sarah. (Hence the title, *On Being Sarah*.) Or was I being Kari? I felt that Kari had wanted me to write this book; you might say it is *her* book.

It is hard to describe the way in which a book like this, truly fiction, can nevertheless be about the life of a real person. The dedication in the book reads: "For Kari, without whom this book could not have been written." This is true. Though a literal account of events in Kari's life would not have made the book I wanted, she is in the book just the same. Sarah learned symbols in a special school, as Kari did. As the

book opens she is about to attend a special class in a neighborhood school. Like Kari. Many details in Sarah's everyday life were provided by Kari's mother. For example, in getting Sarah out of bed and into her wheelchair, her mother, "grasping Sarah tight around the middle, with a quick twist heaved her into it." How could I have known *that* if Ruth Harrington had not told me?

There is a scene in which Sarah and her mother, at Sarah's bedtime, are straightening out a misunderstanding; Sarah is convinced that her mother wants to put her into an institution. Her mother assures her that this is not true: "Why would we do that when you're doing so well here?"

Then, to quote again: "Sarah felt herself in her mother's arms, comforted. Her mother cried a little." "How wonderful," she said, "that you could tell me."

Though the context was different, this is very like what Kari's mother once said to her at a difficult time.

I could cite many such examples. Often when I thought up exciting episodes that never happened to Kari, some of the details would be hers.

The gardens on top of low brick walls, as described in *On Being Sarah*, are like those I saw at Participation House in Markham, where Kari now lives. In my book these gardens are at an institution I call Plainview, suggested to me by Bloorview Children's Hospital in Toronto, where I had visited John Dowling.

The original manuscript of *On Being Sarah* was read by Kari, her mother, and Jinny Storr. Without their help I could never have completed it. Imagine my relief when Ruth Harrington said, "That's just the way it really is!"

As authors often do, I had written much too much; New York editors, though impressed, could not decide

what to do with it. Finally, the editor at Albert Whitman, a distinguished publisher of children's books only, said they would publish it if I would cut it in half. So my book, *On Being Sarah*, is half of my manuscript. The other half, with Sarah a little older, may be published as a sequel. (And that may be the best half!)

Kari has received her autographed copy of *On Being Sarah*. She wrote to thank me in her own handwriting: "Dear Elizabeth, I just got your book, *On Being Sarah*. You can't imagine how I felt when I read that page where you dedicated it to me. I feel so honoured! Thank you! I started to read the book and it is very good. You must be very proud of yourself. You had waited so long to get it published. Congratulations! Best wishes, Kari."

My early book, *Signs and Symbols Around the World*, was only part of what led me to write *On Being Sarah*, but the whole experience with children and their Blissymbols would not have occurred without it. What a wonderful thing to happen to a writer.

Sources for *On Being Sarah*

Canadian distributor: General Publishing Co. Limited, 1800 Steeles Ave. W. Concord, Ont. - \$15.50 Canadian.

USA publisher: Albert Whitman & Co., 6340 Oakton St., Morton Grove, Illinois 60053-2723. \$11.95 US.

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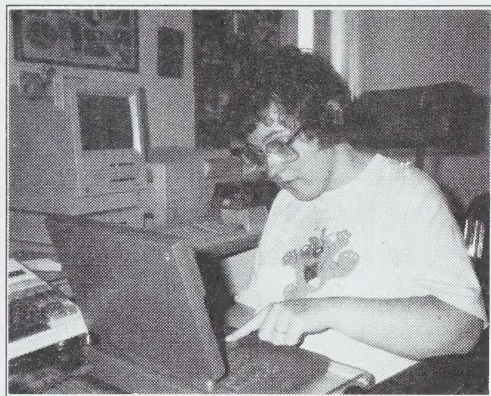
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Relationships with Attendants

KARI & RUTH HARRINGTON



*If you have read the cover story, **On Being Sarah**, you will realize that Kari Harrington, co-editor of this section, had a lot to do with the fictional character, Sarah. In **Living**, she shares her own experiences and insights. This issue, Kari tells us from her first-hand observations how she feels about the relationships between residents and attendants.*

At meetings where people who are disabled gather, the topic of attendants often comes up. Some of those requiring assistance speak out in anger and frustration because the attendants they are involved with don't meet their expectations and efforts they make to change things are complicated by the communication problems between them.

Some consumers wish they could hire their own attendants and then have more control over their lives. They would be the ones to say how and when things are to be done. The attendant would be accountable to them and could be fired by them if the care did not measure up to what they wanted. I know that many people with disabilities are in a position to have this arrangement for

attendant care but I am not one of them. I will be talking about my relationship with attendants in a residence where there is no choice. You have the person to whom you are assigned or someone who is available.

Before moving to where I now live, I attended an Apartment Readiness Course. One discussion was about attendants — what they expect of us, what we have the right to expect of them, and how our attitudes toward them affect their attitudes toward us. It was all quite easy to understand.

The attendants would expect us to do as much for ourselves as we possibly could. One would be assigned to us, as well as to others, each shift. We would be expected to make a plan of our needs ahead of time. If we wanted something extra done, we would have to ask for it and the attendant would try to do it. If it was an emergency, *someone* would help right away.

We should expect to be treated with dignity and respect by everyone and have the right to privacy when we wish it. (Like everyone else, there are times when I don't want to be disturbed but, *I* don't like having my door closed! The Residents' Council, here, agreed upon a simple plan for everyone. A red circle on a door (open or closed) means no one is to bother you. The green one means it's OK. Red light, green light may seem a little juvenile but it works. We can expect attendants to ask our preferences and, when possible, to follow our suggestions as how best to meet our needs. However, we cannot expect special favours from them, especially outside of their working hours.

We talked about consideration and understanding being two-way

streets. We are all just people and if we wish for these things, we must be prepared to give them back to others, attendants included.

During the two years I have lived away from home, things have gone quite well for me. There has been very little change in staff, which means the staff pretty well all know each resident's unique needs and preferences and give us the care we must have. They seem to co-operate with one another and that makes it nicer for us too.

This doesn't mean everything is perfect all the time. There are some faces I am happier to see in the morning than others. Some nights I sleep better because of who has put me to bed. The difference isn't in *what* is done as much as *how* it is done. My outlook for the whole day is much brighter when I am awakened by a cheerful, friendly face. Some attendants just seem to know instinctively the "little things" to do which will make us more comfortable or cheer us up when we are down. They will take the time needed to let *us* talk and will ask us questions: "Would you like me to? or "Would you like to tell me?" or they share some of their own news which takes our minds off whatever is bugging us. Some attendants seem to find the time to do more than their job descriptions require them to do. They find time to style our hair for special occasions, put make-up on us or just sit down to talk. Some arrange their time in order to take one or two of us out to lunch and shopping at the mall. These things are over and above the usual outings arranged by the recreation staff. If we ask, they will help us to arrange transportation so we can go on our own. No wonder we develop "favourites"! Of course,

in order for one attendant to be able to do some of these things, there has to be some of that co-operation I mentioned earlier, between them and the other staff members who cover for them while they're gone. It's important to remember that fact.

There have been a few upsetting incidents for me and some that were just bothersome. I bet everyone relying on attendant care, has been forgotten at one time or another and been left sitting in the washroom for what seems like a long time. That's also happened to me a couple of times when I've been going through a similar routine but have still had my "wheels" under me. For this problem I came up with a solution of my own. I managed to get to my speaker phone, called the front office and asked them to send someone to help. I felt very proud of myself: first, for even thinking of doing it, instead of just sitting there getting more and more frustrated, next, for having the nerve to do it and finally, for remembering the right number to call. Now I've got the number programmed into my phone, ready in case I ever need it again. Once, my attendant was called away as I was about to be dried after my shower. I knew someone would find me before too long, but I wasn't very comfortable and it frustrated me not knowing what was going on. I still don't know why I was deserted.

It used to upset me a lot when I awoke in the night needing help and couldn't get anyone to hear my calls. Regular rounds are made all night. I could hear the attendant's footsteps but when I called, no one came. My voice wasn't loud enough to be heard outside my room. It was an attendant who gave me the solution for this problem. She suggested a light on a pull chain which would hang right beside my bed so I could signal with the light instead of my voice. My Dad installed it right away and now there's no problem.

The most hurtful thing to me personally was when I was first staying here and asked one of the attendants to be careful of my equipment. I have devices and gadgets that need special care when handling them. She seemed to be treating them roughly. She called me a "fuss budget". When I printed out on my Epson how easily these things can be broken, how hard it is to get them fixed sometimes and how I didn't want to have to do without them, she just laughed at me and walked away. It really hurt my feelings. I know I was especially sensitive at that time, however, I think a person who relies on devices has the right to expect that their equipment will be treated with the same respect as they are.

**Attendants are important
because they can make a
critical difference in the
quality of our lives.**

Residents' Council

Last fall the administration at this facility decided to set up a Residents' Council where the residents could have direct input into the activities of the House and could have an acceptable way for unresolved problems to be heard and

agreeable solutions found. The residents elected six representatives to sit on the council. (I happen to be one of them.) They meet once a month and a staff member from Life Skills helps to keep the meetings running smoothly.

Out of one meeting came the decision that when residents have a complaint of any kind, they should be encouraged to communicate it to anyone with whom they feel comfortable. That person will then try to help solve the problem. If this is not possible or the resident is not satisfied with the result, a council representative should be asked to bring it up before the council for input and help from the whole group. I think the administration is advised of the outcome of each meeting.

Communication problems make this a process which takes a lot of time and patience from everyone. However, the council is a really good way to make sure that the resident's ideas on how they would like things to be, can be heard; complaints can be resolved fairly; and better relationships between all attendants and residents can come about. Attendants are important because they can make a critical difference in the quality of our lives.

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AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

*The Official Journal of the
International Society for Augmentative and Alternative Communication*

Editor: **Lyle L. Lloyd, Ph.D.**, Professor of Special Education, Professor of Audiology and Speech Sciences, Purdue University

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Measuring Interface Device Performance

JENNIFER ANGELO, Ph.D. OTR

*Jeff Higgenbotham, associate editor for **Consuming Technology**, has invited Jennifer Angelo, a former colleague, to contribute her knowledge relating to accessing technology. Jennifer was on the faculty of Occupational Therapy at the University of Buffalo for four years. She is now an Assistant Professor in the Department of Occupational Therapy at the University of Pittsburgh. Jennifer is one of the few occupational therapists with a Ph.D. and her specialty is AAC and computer access. She is an outstanding clinician and her research interests have focussed on computer access by severely physically challenged persons.*

Access is an engaging issue. For an individual who is employed, it may mean a smaller than the standard keyboard connected to the computer so the worker can complete job related tasks. For a child with a disability it may mean using a big red switch connected to the popcorn popper to enable the child to make the snack for the afternoon play group. For yet another individual it may be using a head pointer to press keys on an augmentative communication device so that the individual can communicate. All the individuals in these examples have at least one thing in common. They have needed someone to evaluate access methods so they could complete their job assignment, or carry out their ambitions no matter how small or large.

Access methods generally can be divided into two categories. The first category includes adapting standard tools found in the office, home, or school. The evaluator builds up pencils or crayons to make them easier to grasp or builds up the handle of a pointer or places the interface device, (i.e. keyboard) at an angle that increases accessibility for the user. The second category includes adaptive devices that are commonly not used by workers or students. In either case, the user must be positioned properly.

No one, disabled or abled, works at their best if their positioning and seating have not been optimized. At times this can mean that the access assessment should be postponed until the seating and positioning issues have been addressed and rectified. At other times the seating and positioning needs can be corrected with minimal adjustments and the access assessment can proceed. Until seating and position needs are remedied, individuals may fatigue more quickly, make more errors in their work, and be unable to work to their potential.

Many times when an individual is considering using an assistive device to increase independence, the evaluation will begin by examining standard devices found in the environment. This approach is initiated when the motor control is such that using standard equipment is possible. There are many reasons to try and use standard equipment. First, there may be several manufacturers making this type of device. Therefore, there will be a wider selection of items from which to compare and choose. Second, if the item is commonly found and needs repair, the repair can be done locally and

does not need to be sent away. This means if repair is needed that the user will be without the device for a shorter period of time, if at all. Third, if the device is commonly found in the environment many individuals will understand its operating functions. This means that co-workers will be able to make minor adjustments as needed and the technology provider will not have to be called in.

If, due to physical limitations, the individual cannot use standard equipment, devices specifically designed to increase the independence for persons with physical limitations should be examined. This access assessment is usually accomplished by a technology provider who has extensive knowledge about this specialized equipment.

When examining devices it is best to compare them side-by-side. It is not sufficient to only read the advertisement brochures or look at a picture in a catalog. One must actually try them out. The more time that is spent using each device, the more the user will know and understand the subtle differences between them. Each device should be used for a minimum of ten minutes. More time will be more beneficial, but sometimes this is impossible to arrange.

Working with each device in the setting where the device will be used is also useful. Space requirements and work surfaces that are too high or too low become obvious. In addition, if the unsuitable conditions cannot be overcome but must be worked around, it is better to know early in the evaluation process rather than finding out after the device has been purchased.

Adaptive devices should be set up in an optimal way for the user. This relates to the height of the keyboard or placement of the switch. The screen or display should be in easy view for the user to see. Colors should be of a contrast that is easy for the user. Forearms and wrists should be well supported. The user should be given some preliminary instruction and then allowed to explore the device on his/her own.

At times, the optimal set up of the devices cannot be predetermined. In this situation, the assessment tools described below can be used to test the device by changing one variable each time. An example of this situation is assessing an individual who uses her right hand for 90% of her typing and her left hand for only the letters on the very far left of the keyboard and for the shift key. The assessment begins with the keyboard in the midline for the individual and progressively moves to the right. Each time the position of the keyboard changes, it is noted on the scoring sheet and the accuracy and speed scores are recorded. Another example is using the same keyboard with and without a keyguard.

Some of the following evaluation tools have been adapted from the Trace Center and the publication, *Control of Computer-Based Technology for People with Physical Disabilities Assessment Manual* (Lee & Thomas, 1990). The first two tools are for measuring keyboard skills. The third tool is used to document observations that the user and the evaluator notice.

The first tool, the Green Dot Test, measures the motor skill involved in pressing keys on a keyboard. It was developed at the Trace Center, Madison, Wisconsin, and discussed by Smith (1992). Six colored adhesive stickers are placed on the peripheral keys on the keyboard being tested. The user presses each key sequentially beginning and

ending with the same sticker each time. The six stickers are placed in the same position as much as possible for the other keyboards being evaluated. The user repeats pressing the marked keys using the same pattern on each additional keyboard. The user is timed on his/her ability to accurately press the six marked keys. The test is completed a minimum of three times on each keyboard being evaluated. The score is recorded for speed and accuracy.

The next tool adds the cognitive load to the typing task. The user is asked to complete drills 1 and 2 below. Each drill is completed a minimum of three times.

1. Have the user type his/her name.
2. Type a standard sentence using words that are easy for the user to spell.

The speed and accuracy between the keyboards or positions of one keyboard are compared. Consistency of completing each drill the same way for each keyboard is important. Capitalization and punctuation should be either used or omitted in every test. My preference is to omit capitalization and punctuation. *Finding* the letters on the keys is sufficient information to compare the ability of using each keyboard. Sometimes the user spends an inordinate amount of time searching for the key which contains a period or comma and pressing either the caps lock key or holding down the shift key with the non-dominant hand. At this point in the assessment I want to know their ability to easily use the keyboard, not how they will deal with the other issues of typing. Handling the other keys on the keyboard that the user will ultimately need control over is a different issue and should be dealt with separately.

The user should be asked the following questions for each task, to provide additional documentation as to why a particular device was

recommended (adapted from Lee & Thomas, 1990):

1. How tired do you feel from using this device?
1 = very tired, 2 = neutral, 3 = not tired
2. Was the keyboard easy to read?
1 = difficult to read, 2 = neutral, 3 = easy to read
3. Did the tension in your body change using this device?
1 = increased, 2 = stayed the same, 3 = decreased.

The evaluator should record scores and ask the user these questions at the end of the test session for each device. Sometimes it is necessary to assign another member of the assessment team to observe one category and record the information in addition to asking the user to respond to the questions.

Other questions to be asked are:

1. Which manual has the best documentation for each device?
2. Which manufacturer gives the best technical support for their device?
3. Are there studies, consumer reports or reviews of the devices being evaluated?

Conclusions

In this article I have briefly described some basic evaluation tools that can be used for collecting information on different types of input devices. Information collected in this way helps to quantify the user's ability to use assistive devices in a relatively short period of time. This information also provides supporting data when recommendations for assistive devices are made.

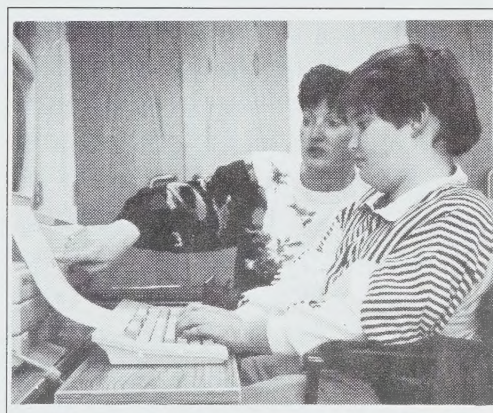
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TEACHING AND LEARNING

Keyboarding Instruction by Correspondence: "Let Your Fingers Do the Talking."

CATHY VITEZ



Robert Haaf, one of our associate editors for Teaching and Learning, has invited Cathy Vitez to share her role and the program she has developed as the written communication instructor for the Augmentative Communication Service at the Thames Valley Children's Centre in London, Ontario, Canada.

Isn't technology wonderful! In our fast paced society, all we have to do is look around to see the explosive development of computer technology. Wish for a device to make our lives easier and poof...we have it, or we hear it's already on the drawing board. What more could we want? But wait...perhaps we need to slow down a bit and ensure that the equipment we already have is being used effectively, in particular technology for written communication. For clients who have been identified

as needing a piece of equipment to facilitate their written communication, selecting a device is easy. The challenge lies in developing keyboarding skills that will allow users to utilize the device optimally. Basic keyboarding instruction can make the difference between a dusty computer sitting in a corner and the development of proficient keyboarding skills for creative and effective written expression.

Keyboarding Instruction at TVCC

Thames Valley Children's Centre has made great strides in supporting the development of keyboarding skills for clients with written communication devices. It all began several years ago when our clients displayed their frustration of having access to a writing device but, due to lack of training, being unable to use it effectively. Our keyboarding instruction programs have come a long way since then. Individualized instructional programs have been developed, for a variety of access methods, ranging from two handed touch typing to adapted access (expanded keyboards, switches, etc.). The ultimate goal is always the same: independent and functional use of the keyboard for written communication.

A Day in the Life of an Instructional Program

To illustrate the structure of keyboarding instruction programs offered by the Augmentative Communication Service at the Thames Valley Children's Centre, let's meet Brian. Brian is 10 years old and has cerebral palsy. He is a typical grade

4 student in his community school. Brian loves all sports, especially baseball. Until grade 4, Brian had managed quite well using pencil and paper to complete written communication tasks. Grade 4 presented increased written demands, causing Brian to fall behind his classmates. He was frustrated with his inability to complete the required work.

Brian's parents arranged for a referral to be made to the Augmentative Communication Service for a written communication assessment. Brian's written communication skills were assessed by an occupational therapist and recommendations were made. It was determined that Brian would benefit from the use of a keyboard to facilitate his written communication. During the assessment, Brian demonstrated the physical ability and motivation required to access the keyboard using both of his hands. A referral was made for a two handed touch-keyboarding instruction program.

Components of the Correspondence Program

As part of the correspondence program, Brian would be involved in structured lessons for 20 minutes daily. Lessons, and the required materials to carry out the lessons would be provided by the written communication instructor at the Centre. Completed lessons would be mailed to the Centre once a week in the stamped envelopes provided. Once the lessons arrived at the Centre, they would be reviewed and program revisions made as appropriate.

Prerequisites for the Program

Before Brian's instruction program was initiated, three important questions needed to be answered: *Where* would Brian complete the instruction program, *who* would take responsibility for ensuring that daily lessons were completed, and *what* equipment would he use?

1. Location

To determine location, the environment(s) where the keyboarding skills are most needed must be established, as it makes sense to conduct the instruction in that setting. It was therefore decided that Brian's keyboarding instruction should take place at school, provided the other prerequisites could be met in that setting.

2. Program Provider

The role of the program provider is critical. This person would take responsibility for Brian's keyboarding program, and would need to be available to work with Brian for 20 minutes daily as he completed his lessons. It was essential to the success of Brian's program that the designated person be committed to the program and recognize Brian's need to develop keyboarding skills. Brian's resource teacher, Mrs. King, was selected. With some rescheduling, she was able to commit the necessary time, energy and enthusiasm. Mrs. King was already seeing Brian three times a week, and she was able to incorporate the keyboarding goals into his program. The resource room was chosen as the location for the instruction. It was quiet and had few distractions.

3. Equipment

As the school's resource room was equipped with an electric typewriter and a computer, either one could be made available for Brian's use. Generally, a keyboard is the same, whether it is on a typewriter or a computer. However, there were some additional variables influencing the choice of equipment. The electronic typewriter had the advantages of being lightweight, portable and providing immediate printed output.

On this basis it was a reasonable option, but it was quickly ruled out. Previously, Brian had used the computer for learning games and he was very motivated and eager to continue using it for his keyboarding lessons. The computer allowed Brian to see the text he typed on the screen, and the computer keys were easier to depress than those of the typewriter. All of these factors resulted in the computer being chosen for Brian. To go along with the computer, Brian would need an appropriate word processor and printer. A printer was already available for use in the resource room. Microsoft Works was one of the available word processing programs. This program is a complex word processor with many features and functions, but based on Brian's high academic standings it was felt to be appropriate for instruction.

Orientation Session

The goal of the orientation was to familiarize everyone involved with the components of the correspondence program and to make them comfortable with what was expected. It took place in the school, and in attendance were Brian, Mrs. King, Brian's mother and TVCC's written communication instructor.

During the orientation session, instruction information was shared, specific programming decisions were made, and materials were provided. Timed keyboarding tasks were completed by Brian, as a baseline for comparison of his pre- and post-instruction keyboarding speeds.

Clinical Agreement

A clinical agreement was drawn up which outlined the following: Brian's level of functional keyboarding prior to keyboarding instruction; those skills Brian was expected to achieve once instruction had been completed; the detailed steps which needed to be taken to achieve the goals; the time lines; and the designated responsibilities of all involved. The clinical agreement was developed by, agreed to, and signed by

Brian's program provider, Mrs. King, and the written communication instructor. Mrs. King and Brian's parents were given copies of the clinical agreement. Although Brian's parents were not directly involved with the implementation of the keyboarding program, contact with them was maintained throughout. They were updated on the progress and status of Brian's program, especially when changes occurred.

Communication and Commitment

The success of Brian's keyboard instruction program was greatly dependent on Mrs. King's commitment and involvement. The short notes she sent to the written communication instructor along with Brian's lessons provided a good indication of how things were progressing. Successes were reported, as well as obstacles requiring program intervention.

One month into Brian's lessons, Mrs. King reported that Brian was experiencing great difficulty in keeping his fingers on the home row keys without relying on visual feedback. Mrs. King was provided with soft velcro tabs for placement on the home row keys. Over the next couple of weeks, Mrs. King reported that the tactile feedback of the velcro had decreased Brian's need for visual cues. When Brian became more familiar with the location of the home row keys, Mrs. King was advised to remove the velcro. The next note received from Mrs. King indicated that Brian was now able to keep his hands on the home row keys without difficulty.

Continuity of Correspondence

All correspondence relating to Brian's keyboarding program was recorded on a *flow sheet*. The flow sheet included a brief description of Brian's keyboard access, the lesson package, equipment and software

used, and an ongoing record of when correspondence was sent to and received from Brian.

Within two days of receiving lessons from Brian, he was sent a short letter which often included words of encouragement, sports stickers, and additional recommendations for improving his keyboarding skills. Since sports trivia was very motivating for Brian, we enjoyed sharing sports facts in our ongoing correspondence. At one point during Brian's lessons, it became apparent that his enthusiasm was starting to dwindle. Much to Brian's pleasure, a new reinforcer was introduced: Brian accumulated achievement points which were traded for baseball cards! For each line Brian typed successfully, he was given one point. Points were tallied until Brian had 25...enough for a package of baseball cards. As well as giving Brian positive feedback and encouragement, a very deserving Mrs. King was given periodic notes of encouragement, particularly when Brian started to lose his motivation for completing the program.

Reassessment of Keyboarding Skills

Correspondence lessons were completed by Brian for a period of six months. Following the completion of the two handed keyboarding lessons, Brian's keyboarding skills were reassessed. Keyboarding techniques and post-instruction speed scores were obtained. Brian demonstrated that he had gained familiarity with the location of all the letters on the keyboard using the two handed method of access, but he lacked the confidence to type consistently without looking at his hands. No further structured lessons were necessary; what Brian needed now was to use his keyboarding skills functionally, to develop the confidence necessary to type with increased speed and proficiency.

Keyboarding Integration

A meeting was scheduled with school personnel to determine Brian's written communication needs in the classroom and how his keyboarding skills could be used to complete written assignments. In attendance for the meeting were Brian, Mrs. King, Brian's classroom teacher, and his occupational therapist, who had been working with Brian to develop his cursive writing skills. Brian's parents were made aware that the reassessment was taking place. Although they did not feel they needed to attend the session, they wanted feedback about reassessment findings and the status of Brian's future instruction plans.

Brian had learned two handed keyboarding skills, but instruction did not stop there. Functional integration of his keyboarding skills represented the next goal to achieve. With input from all those in attendance, a set of functional keyboarding goals were established. It was determined that Brian would use his computer to type his daily journal entries and spelling exercises. Correspondence intervention continued as Brian sent copies of his journal and spelling exercises for review.

Integration Success

Following the six week functional training period, another visit was made to the school to assess whether Brian's functional goals had been successfully achieved. Based on the written work that was sent to the Centre and the reassessment of Brian's keyboarding skills, he could be considered a proficient keyboard user. Brian was actually one step ahead, in that he had already used his keyboarding skills for subjects in addition to those originally outlined in the clinical agreement.

The use of the classroom computer had worked out very well for Brian as he completed functional assignments during the six week period. Brian's classroom teacher

could not see any reason why this arrangement could not continue.

Brian is now a functional two handed touch keyboarder. He is able to keep up with the written demands in the classroom and is thrilled that he is the envy of his classmates for his keyboarding abilities. Brian had become an official "Keyboarding Whiz Kid," and he now had a certificate to prove it!

Keyboarding instruction by correspondence has been a very successful program in the Augmentative Communication Service at the Thames Valley Children's Centre. The evolution has been tremendous: Currently, there are 44 Centre clients on correspondence programs. The greatest achievement has been the ability to empower clients and their program providers to play an active role in the success of their instruction program.

The correspondence program continues to evolve. As our clients' needs expand and technology becomes more a part of the classroom setting, more specific instruction in word processing and in learning complex programs is required, to the point where currently 60% of the active programs involve word processor instruction. Regardless of the specific tasks and goals, the overall structure of the correspondence program is the same.

Realistically, instruction programs are not always as successful as Brian's, but the positive results far outweigh the setbacks. The feedback from clients, school personnel, parents and other professionals has been very encouraging. We now know that slowing down in our fast-paced society, to ensure the most effective use of written communication technology, has helped our clients become more satisfied as they "let their fingers do the talking!"

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Reviews and Plugs

GEB VERBURG

As the title, *Children with Cerebral Palsy* indicates, this is a book for parents with a child who has cerebral palsy. It is written by the people who are involved in the care and treatment of children with cerebral palsy including two parents and ten professionals, and is edited by a parent. Ten chapters each of approximately 35 pages deal with issues from "What is Cerebral Palsy?" via the what's, who's, and when's of treatment and development, to legal rights and advocacy issues.

Chapters one and three written by a medical doctor address the issue of what is cerebral palsy and what are the medical concerns. I found chapter three especially daunting reading because of the long list of ailments and conditions to which a child with cerebral palsy is or may be more prone than the average child. Medical and technical terms are introduced and explained at a level that is simple and accurate.

My two favourite chapters of the book are chapters two and ten. In chapter two: "Adjusting to Your Child's Disability," Rita Burke discusses the shock of finding out that one's child has a disability and the emotions that arise: denial, grief, guilt, anger, and resentment. Ms. Burke comments that parents need to take time to deal with their emotions

before being able to adjust to and to accept their child. She warns against being overprotective, something that many adults and certainly new parents are likely to be with a child who has a disability. Key factors in my opinion are to (learn to) accept your child, accept the disability, get the facts, and never lose sight of the fact that you are in charge of your child's life and your own. Family dynamics, e.g., impact on the marital relationship, how siblings react, how to tell the grandparents and friends are included. This chapter like all others concludes with "Parent Statements" which generally cover the entire gamut of opinion and emotion and will allow parents to find themselves.

Ms. Smith, a mother of four wrote Chapter 10, entitled *Some Lessons Learned about Advocacy*. According to Ms. Smith the three keys of advocacy are "commitment, knowledge, and skill" (p. 337). Each of these key components is discussed. I want to share a long quote from Ms. Smith with you :

"Through my advocacy work, I have learned that the welfare of children like yours depends on your family being as informed and as strong—as empowered—as it can be." p. 334. She continues:

"I have often wished that when parents hear the diagnosis of cerebral palsy (or any disability) they could receive a 'how-to' manual on everything they should know about the condition, the services their child will need and where to find them, all the laws pertaining to their child, and how to be an effective spokesperson for their child when services are not readily forthcoming." p. 334.

She notes, and I concur wholeheartedly, that "this book is a good start at preparing you to meet the challenges you will face throughout your child's life." p. 334. Chapters four to six address topics of *Daily Care, Family Life and Self-Esteem, and Your Child's Development*. These three chapters are about you and your child, the daily care routines all the way from holding and positioning advice to babysitting hints, family issues, and elaborate developmental milestone charts.

Chapters seven and eight are set aside for discussions of the assessments, training or treatment routines of the physical, occupational, and speech language therapists, and special education practices and laws. Augmentative Communication is mentioned in this chapter but receives limited coverage (p. 252). Finally, chapter nine gives a review of laws, regulations, acts, and facts about insurance, estate planning, wills and alternatives. All this applies of course to the United States and will require adaptation to your country's laws and customs.

At the end of the book are enclosed a 16 page Glossary, a nine page Reading List (by chapters), a limited list of special equipment suppliers, and an extensive resource guide.

Critique

The book is timely and I would guess extremely helpful to parents of children who have cerebral palsy and probably to other parents of children who have other disabilities because many of the issues covered, especially those dealing with the emotions and family and societal

dynamics, will be very similar across disabilities. Great book. Highly recommended. It is a book that addresses the most common forms of cerebral palsy, i.e. not the extremely severely involved child. That is in itself probably not a serious criticism. However it means that parents of children who are severely physically involved and non-speaking must look elsewhere for additional information.

And last, and again this is not so much a serious criticism, as a request for inclusion in the next edition. The one major omission of the book is that it does not explicitly address vocational training. Until the children become 18 or 22 years of age employment is not ordinarily on the minds of parents or professionals. And that is a grave mistake. I recently received a survey that I was asked to forward to a person who uses an AAC device and who has a job. The survey intends to find out what are the contributing factors to successful employment of persons who use AAC devices. Much to my surprise, among the ten people I know who use an AAC device I could only find one who held a part-time job. Vocational training or at least the conviction that this child will be employed when s/he grows up must accompany every intervention that takes place. We must believe that children with cerebral palsy or any other disability including users of AAC devices are able to hold jobs. And we therefore must train, teach, condition, expect, according to these beliefs. Because if we don't believe that the children are equal then who will?

Let's Talk

One of the alternative resources required for parents of children who require AAC technology could be a video produced by the Augmentative Communication Services of the Hugh MacMillan Rehabilitation Centre. The video which is called "Go Ahead ... Talk!" comes with a compact resource

guide which restates and emphasizes the points of the video conveniently listed or charted; the booklet also contains a definition of terms, a workshop outline, and a list of resources. People who work or come in contact with persons who use AAC devices (e.g., new parents, therapists, teachers, medical doctors) are among the intended audience and so are people who work in service areas such as stores, banks, hospitals, libraries and government offices. I would recommend that every school and every public library have at least one copy available.

The 11 minute video is a very clear, appealing, and understandable way of explaining what Alternative and Augmentative Communication is. A puppet is introduced which provides a means of carrying the story-line, and allows the asking of awkward but necessary questions which are in the audience's mind. The puppet also adds fun and a character with whom the audience can easily identify.

Information about *Go Ahead ... Talk!* (Can \$ 75. + \$ 3. shipping to buy or \$25. to rent) can be obtained from the Instructional Media Services Department, Hugh MacMillan Rehabilitation Centre, 350 Rumsey Road, Toronto, Ontario, Canada, M4G 1R8. Fax (416) 425-6591.

Lorenzo's Oil

I wanted to invite those of you who can spare a few hours to go and see this movie by director George Miller. Nick Nolte and Susan Sarandon play the roles of real life Augusta and Michaela Odone who have a son with Adrenoleukodystrophy (ALD). ALD was a terminal disease in which the mal- or non-function of an enzyme causes the storage of surplus long-chain fatty acids in the brain where these acids dissolve or attack the brain's nerve cell's myelin sheaths with the expected terrible consequences. The film tells the

story of how the Odone's within ALD's inevitably deadly chronometer of about 24 months manage to find a therapy that stops the progress of the disease and stabilizes their child's condition.

I hope to review this film with some colleagues in the next column because it has some marvellous conflicts in it between the empowered parent and the medical professional, between the specialists and the holists, issues about the tyranny of method and the selling of hope. In order not to set your expectations wrong, a pop-mag in Toronto called the film "an overly long disease-of-the-week TV movie helped along by some nice directorial moments and intermittently strong performances" (EYE, Jan 28, 1993, p. 39).

International Newsletter on Sexuality and Disability

As a follow-up on the issue on Sexuality I would like to mention a new international consumer-written quarterly newsletter on sexuality, sex and disability. *It's Okay* is published by Phoenix Counsel Inc., 1 Springbank Drive, St. Catharines, Ontario, Canada, L2S 2K1. Linda Crabtree is the newsletter's publisher and editor. Annual subscription costs are \$ 23.95 plus \$2 shipping if you live outside Canada.

Reference

Children with Cerebral Palsy: A Parents' Guide. (1991), Elaine Gerasis (Ed). Woodbine House. ISBN 0-933149-15-8. The price in my (library) copy was US\$ 14.95 §

Have You Moved?

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Facilitated Communication: Some Further Thoughts

ROSEMARY CROSSLEY

We were delighted to receive the following letter from Rosemary Crossley responding to the theme in our last issue — Facilitated Communication.

The December 1992 issue of **Communicating Together** devoted to facilitated communication has just arrived at DEAL. Congratulations – overall you have a good range of articles and opinions on what is, understandably, a controversial subject. Of course there are a few inaccuracies of fact or interpretation, but realistically they are impossible to prevent (as anyone who's ever worked in AAC is fully aware!).

Your comments in the editorial on the indiscriminate application of facilitated communication (FC) are particularly apposite. During the time I spent in the U.S. last year I was asked to see or assess a number of individuals. Often the reason I was being asked to see these people was because they had "failed" with FC, and it was thought that I might be able to wave a magic wand (or something). In many cases my first reaction was astonishment that these individuals had ever been considered as candidates for facilitation, in that the severity of their physical impairments was such as to preclude them using their hands for direct access with facilitation, much less for independent direct access. On suggesting other access options such as eye-pointing or switch-training it

generally became clear that no other AAC options had ever been considered, and that teachers and caregivers were often unaware that they existed. As far as I know, not one of the children or adults with CP that I was asked to see had ever had an AAC assessment, though most of them were attending schools and were being seen by an SLP. To indicate the depth of ignorance about both AAC and FC, one question which I was asked several times was "How do you facilitate someone with spastic quadriplegia who is blind?" My answer "You don't!" was neither expected nor appreciated. To put facilitation in perspective, in the graduate course on AAC I gave at Syracuse last semester just three out of 39 hours of face-to-face contact were allocated to facilitated communication training (FCT).

Three articles in **Communicating Together** cited the case of "Carla," with varying degrees of accuracy. Briefly, Carla is a woman in her twenties who was left with movement planning problems and virtually no intelligible speech after an attack of infantile encephalitis. At the end of 1990 (ironically while I was attending the TASH conference in Chicago) Carla, who was typing with facilitation, told a number of people, including independent facilitators, that family members had assaulted her. The ensuing mess took great toll on Carla and her family and pointed up a number of deficits in our abuse protection bureaucracy. Eighteen months later a Guardianship Board hearing found that Carla was severely retarded and could not communicate through spelling. The case was not a court

case, there was no judge involved, and the rules of evidence did not apply.

The reason I still believe in Carla's ability to communicate through spelling, though not the allegations, which always appeared inherently implausible,¹ is because in mid-1990 she had just reached the stage of being able to type single words and short phrases without facilitation. The Board refused to see Carla communicate in person and implied that I had somehow faked her communication on a videotape on which she is seen typing with my hand on her shoulder but no other support. The communication tests were done with a new and untrained facilitator. Intellectual assessment was based on the Performance Scales of the WAIS and Stanford-Binet, scarcely an ideal measure for a person with major motor planning problems. After the hearing Carla was removed from her day program and isolated in the family home without access to any form of non-speech communication.

Certainly I do not see Carla as one of our successes – I don't see anyone emerging from Carla's case with much credit. Nonetheless, it is quite incorrect to state, as Stephen von Tetzchner does, that my belief that Carla can communicate through facilitation implies belief in her allegations. Two of the commonest misapprehensions about FC are:

If it's spelt it's true

and

*If it's false it wasn't spelt
(or at least not by the person who is
being facilitated)*

There seems to be an extraordinary belief out there that individuals with severe communication impairment (SCI) always tell the truth, and never exaggerate, fantasize, dream or confabulate. Any communication that is not factually correct is assumed to emanate from the facilitator, not the aid user. Equally, any spelt communication, however inherently improbable, is likely to be believed and acted upon without question. As well as the obvious logical flaws of each assumption, they both ignore the possibility of language and literacy problems in the aid user, the relative lack of pragmatic skills and social *nous* in people who are just starting to use communication aids as adults, and the special vulnerability of virtually all AAC users to misinterpretation. I've written at greater length on this and validation testing, in two chapters in the DEAL booklet, *Facilitated Communication Training*,² called "Who did what and to whom?" and "Who said that?"

In fact, one of the few gaps in the coverage of FCT in **Communicating Together** was the lack of any "how and why" references. Anne Archer says I write from the heart (I would prefer to write from the head, given an option) and refers to my clinical examples, but she does not cite anything I've published, though she cites other articles from the same journals. In fact the most useful reference would probably have been to the article I wrote on FCT which was published in **Communicating Together** 9(2), in June 1991. It was fairly basic and may have oversimplified some aspects of FCT but I don't resile from it and it provides a short introduction for people who have never heard of facilitated communication before.

Possibly because some contributors were not sure of the "how and why" (or at least what DEAL suggests is the how and why) themselves, there was less appreciation of facilitation as an educational strategy than I would have

hoped, given that my preferred term is "facilitated communication *training*" (FCT rather than FC). You quote me correctly as describing facilitation as "a means of training manual selection skills" and that is how it appears to have been used (and very nicely too) by Pierce and Tweedie and Paul McPhail.

Archer and Von Tetzchner, who seem to be writing from an academic perspective rather than from clinical experience, appear to view facilitation as a switch which can be either on or off. As they see it, an individual either can or cannot communicate with facilitation (and by communicate they appear to mean type, though again you quoted me correctly as saying FCT "is not directly connected with typing or literacy"). While at the end of the day that statement is correct – Jane can or cannot communicate successfully when she is facilitated to make selections from objects, pictures, Blissymbols, written words, letters or whatever – it ignores the need for lengthy training and reassessment before a definitive statement can be made about Jane's capabilities.

I once spent several hours a week (as I am sure most AAC practitioners have) for six months teaching a girl to select symbols for "yes" and "no" meaningfully – at the start she couldn't do it; at the end she could. How would you describe her in the middle when her performance on tests was problematical? It would be incorrect to say she could communicate reliably using "yes" and "no," but to say that she couldn't would be to ignore her progress and suggest that she would never acquire the skill. It would be more accurate to describe her as a learner. Likewise with the user of facilitation – failure on a test indicates the need for more training on the part of the aid user or facilitator (or that the test is inappropriate for this individual – Carla, who had major word-finding problems was assessed on a confrontational naming task). It

does not indicate that the aid user has no skills, nor that these skills cannot be extended or improved.

Recently I read what purported to be a manual on FCT (written by two journalists with no AAC background) which said that if facilitation was going to work for an individual you would not need to teach the individual to spell! Now, I certainly have found some individuals with unrecognized literacy skills, but they are by no means universal. Lack of literacy does not mean that an individual does not have the potential to acquire literacy – as Annalu Waller mentions, Anne McDonald was not literate when I started to use facilitation with her in 1977.

My experience at DEAL, which sees a far higher proportion of ambulant adults with developmental disabilities than any other AAC centre I know, is very encouraging about the potential of such individuals to learn to use written language once they realize how empowering it can be for them. More than ninety percent of those who entered the FCT program acquired sufficient spelling skills for spelling to be used as a communication strategy (often in combination with other strategies, such as symbol or word and phrase displays). My view is that all individuals should be treated as if they have the potential to acquire literacy skills and given (at least) the amount of exposure to written language which is given to non-disabled children. I believe that literacy can only be ruled out as an option after a student has been given ample opportunity to acquire it.

I also am worried about youngsters with CP "becoming increasingly dependent on facilitators . . .". While Anne McDonald³ is not a great publicist for independence her circumstances were very different from those of the young children with CP I see now. In fact, throughout North America I found a major problem convincing parents and teachers of

children with any diagnosis that independence is a desirable and achievable goal. At DEAL children with severe physical impairments rarely use FCT and the caregivers of those individuals who do go into the FCT program are given, on the first day of starting the program, a paper on fading support, which may contribute to an expectation of independence.

In a recent piece for the World Rehabilitation Foundation on my impressions of the use of FC in North America I address some of the issues which you raise and identify several common myths about FC:

- the belief that facilitated communication is the best or only communication strategy available for people without speech
- the belief that facilitation is linked to spelling, that only people who can spell are suitable candidates for FCT, and that many individuals with severe communication impairments have a mysteriously acquired ability to spell
- the reluctance to interfere with "natural" behaviors of people with severe communication impairments despite the adverse effects that these behaviors may have on the achievement of independent communication aid use
- an uncritical acceptance of typed communication, including allegations of abuse and claims to have para-normal abilities.

Unfortunately it is not easy to halt a speeding train, especially an American train. I go on to say:

This mythology has probably grown up because facilitation has spread so rapidly in North America, and often programs have been implemented by caregivers or teachers who have heard about facilitation through the media. Some professionals have criticized Biklen and others for the uncontrolled spread of FCT.

To an outsider, this seems absurd. The spread of FCT reflects aspects of American society that are not controllable by any individual. Many of these are positive – in North America I found a much more positive attitude to people with disabilities overall than generally prevails in Australia.⁴ Australians tend to believe the worst about anything and have a great faith in professional opinion. It would seem that the greatest crime an Australian professional can commit is to raise false hope. Any statement about the potential of an individual with disabilities is always likely to err on the negative.

In the U.S. I found a widespread willingness to ignore negative assessments or labels that is rare in Australia. In Australia many professionals feel that their intervention has been successful if they have brought the parents of a child with disabilities to a "realistic" acceptance of the child's limited potential for improvement. Of course if the child later makes unexpected improvements or does things, such as spell, which challenge the negative information reiterated repeatedly to the parents, a major re-adjustment will be required which many families will find difficult or impossible. In North America it appears that many more parents and professionals remain open to the possibility of improvement in a child with disabilities. Consequently there is a more active interest in therapies which appear to offer hope of improvement. While this may mean that some "way-out" therapies are given too much credence, it also means that there is less likelihood of an individual missing out on a potentially beneficial treatment. Associated with the hope of improvement is the inexhaustible appetite of the North American media for human interest stories, such as stories about unexpected achievements by people with disabilities. These positive stories will inevitably be picked up by the parents and teachers of people with similar impairments.

It is imperative that sensible, as opposed to sensational, information on FCT is distributed as widely as possible. If not, the problems resulting from inappropriate use will only increase and there is a real risk of the baby being thrown out with the bathwater.

My thanks to you at **Communicating Together** for your efforts to redress the balance.

Rosemary Crossley

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Footnotes

1. Carla made the allegations to at least 9 facilitators, of whom I think I was the last. The allegations become progressively more lurid and less probable as time went on, so by the time I heard them they were way over the top. My disbelief must have been clear because Carla complained that I didn't believe her (while typing with my hand on her shoulder).
2. Available from the Facilitated Communication Institute, Syracuse University, N.Y. 13244.
3. See Harrington, K. (1988). "A Letter from Annie," **Communicating Together**, 6(4), p. 5.
4. I was travelling with a woman who has severe cerebral palsy and cannot talk. At U. S. Immigration the officer asked the nature of her disability and when told it was CP said "Oh right – she'll understand everything I say, then." This is very different from current perceptions in Australia.

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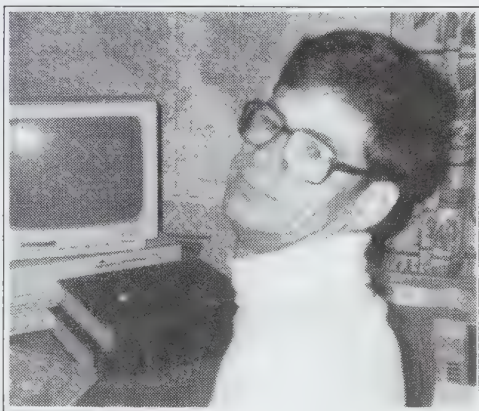
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The Culture Barricade

PAUL MARSHALL



*Paul looks forward to some conversations with other augmentative communicators in **Paul's Place**. Until he receives letters from readers, however, he will be telling us more about his own thoughts. We hope you will join him!*

The Jailer puts the key into the lock, to unlock the door to the outside world. For many of us that key unlocking many doors was the key of communication. Through many locked doors we have come. Through many locked doors we need to go. The world is still a foreign land to many of our issues as nonspeaking and handicapped individuals. As we go into the twenty-first century we must realize it is our future and it is our duty to set up the blueprint for a better tomorrow. Although many people will help, this task of mapping out will be on our shoulders and no one else's.

Let's face it, very few people meet the norms of any society. In Canada three out of ten Canadians have a reading problem. This

greatly alters their opportunities. Health problems, employment cut backs, abuse in families and countless factors alter peoples' lives. People with "handicaps" are members of a subculture who don't meet the standards. We shouldn't look for an easy way of life in a society filled with all ranges of disability. We need to ask ourselves, as a society, "Are we setting the standards too low for the population with a disability?"

How do nonspeaking individuals fit in? When society sets low goals, we are not expected to go to college or to university, get jobs, get married, have families or be owners of land or houses, and the list goes on. It is easy to have a feeling of very low self-worth if one is a member of the nonspeaking subculture. Not many of us are allowed to question and be given the opportunity to wonder. Without this option being given to this cultural group, it will always be a drain rather than a contributor. Is this what we need or want? For any person to have self-worth, there is a need to have a purpose. Without this our lives become meaningless and full of self-pity. One of the greatest things that society can give to anyone is to be needed and have a feeling of usefulness in one's world. This culture barricade badly needs to be addressed as we move ahead into the twenty-first century.

I was blessed to have the starting tools given to me in time, making me want to be a survivor. What if you couldn't communicate, the world couldn't hear your voice and you didn't have a voice to be heard? When you have the tool named communication, would you know how to get the most out of this newly

found tool? This is a real struggle I believe for some nonspeaking individuals. We give them the tool and only sometimes think they have the drive or the knowledge to move ahead and live life with a "handicap."

Here too, there is a cultural barricade. We need to realize, now that we are communicating, that we need the life skills and the feeling of self-worth to live life. We need to learn that the world will not give us the same opportunity as a "normal" member of society without fighting each step. Is society trying to teach us that we don't need these skills or the self-worth? All we need to know is that we will be protected from the falls therefore from the growth. Is this what we want? If not, what are we doing or what are *you* doing about your future?

As more locked doors are opened, the pendulum is swinging to us — the nonspeaking members of society. It's our duty to be survivors and front-runners, to be out breaking down barricades. I was reminded of a friend who is in a country much less fortunate, fighting with all her might trying to unlock a few closed doors for her nonspeaking kids. We who live in the developed countries are like the Jailers now. As we unlock more doors for the nonspeaking in our own communities, we can be front-runners opening opportunities for the nonspeaking around the world.

The old mailbox is getting more rusty as it waits for a letter from you. Give your feedback and let's grow by sharing at *Paul's Place*.

§

Language! Just What Do We Mean? Continued

SHIRLEY MCNAUGHTON

Thanks to Eric Nyberg and the team from The Carolina Literacy Center, we have two thoughtful articles in response to the December, 1992, **SymbolTalk**. As resident editor of **SymbolTalk**, I'm very pleased to

have some attention focused upon symbols and language. Eric deals specifically with some issues raised by Margareta Jennische and extends our understanding of the many ways in which the term "language" is used. The team members from The Carolina Literacy Center emphasize that AAC users should be encouraged "to combine whatever symbol system they

are using *according to the constructs of the language(s) they would be speaking if they were able to do so*" (italics added). The type of dialogue begun by Margareta and responded to by the **SymbolTalk** contributors this issue is a wonderful way to stimulate our learning. I urge others who are interested to continue the discussion!

Linking Symbols with Language

THE CAROLINA LITERACY
CENTRE GROUP



Welcome to Patsy Pierce, Assistant Director for Training, Jane Steelman, Assistant for Technology, David Koppenhaver, Associate Director, and David Yoder, Director at the Carolina Literacy Center — all involved in research relating to literacy instruction for pre-school and school-aged children with disabilities.

In the November issue of **Communicating Together**, Shirley McNaughton and Margareta Jennische raised some interesting and valid questions about characterizing Minspeak™ as a language and subsequently about the efficacy of using Minspeak™ as a communication system for all persons beginning to develop language form, content, and use.

Our characterizing Minspeak™ icons and the rules for combining them as a language is for practical purposes rather than a theoretical one.

Bruce Baker and his colleagues invited us to examine ways to facilitate literacy development in Minspeak™ users. Many teachers, clinicians, and researchers in the field of AAC know that at least 70% of the persons who need to rely on *any* communication output mode other than speech (e.g., sign language, picture communication systems) have significant literacy learning difficulties (Koppenhaver & Yoder, 1992). There are many reasons for their literacy learning difficulties. One possible problematic area appears to be that persons who use coded AAC systems which have different syntactic, semantic, and pragmatic properties (e.g., Minspeak™, American Sign Language) than those existing in the language of their environments need to translate their native language into this new code. We question the effects of using a different icon-based code for face-to-face communication on the AAC user's literacy learning, especially when the AAC system code is also used for writing.

Written language usually maps fairly directly onto the phonemic, semantic, and syntactic properties of spoken language. In referring to Minspeak™ as a language, we are inviting all symbol system developers and instructors to more directly link the rules for combining symbols to the properties of the AAC user's native language. In other words, make the

AAC symbol combination rules those of the syntactic, semantic, and pragmatic rules of the native written and spoken language. In this way, literacy and spoken language development may be more easily acquired because the AAC user is not asked to learn a code into which his native spoken and written language must be translated for production (output).

All modes of communicating, listening, speaking (augmented speaking), reading and writing develop together and each mode helps the other in understanding and in use (Sulzby & Teale, 1991). We should, therefore, use the AAC user's ways of communicating to develop literacy and vice-versa. We must also remember to encourage our developing AAC users to combine whatever symbol system they are using according to the constructs of the language(s) they would be speaking if they were able to do so. When we program voice output devices to speak for AAC users, we must use the developmentally and culturally appropriate content and forms of the user's native language. We may not be able to encourage appropriate language use all the time for the sake of speed in effective face-to-face communication, but we must give developing communicators access and opportunities to practice using the language of their environment via whatever communication tools so that they can get feedback

(expansion, correction, praise) necessary for the development of communicative competence.

Since all modes of communication develop interactively, we must give AAC users opportunities to spell out words and to write sentences using traditional orthography. We know this is not the fastest way for them to communicate but it is important if they are ever going to learn how to spell, how to write, and how to read what they and others have written. Rate enhancement techniques like multiple meaning icons and prediction are essential for efficient communication, but to become effective in both oral and written language, AAC users also must be given the chance to actually use all the interrelated components of communicating (e.g., phonology, morphology, syntax, pragmatics) during some portion of their daily lives.

We have never intended to suggest that Minspeak™ or any other symbol system is better than another in facilitating communication development in AAC users. We believe that

each person has his or her own set of abilities and learning styles that may better match the differing characteristics of the symbol sets available to give a person with a severe speech impairment a way to communicate. Having a way to communicate and something to communicate about is essential to developing the nuances of language, if this is possible for the individual. Our mission in all of our written and spoken presentations is to:

- convince our audience that understanding and using written language at some level is possible, functional, and essential for persons using AAC systems;
- promote the idea of giving developing AAC users the “benefit of the doubt” and to involve them in print-related activities because we do *not* know what their potential may be. We *do* know that reading to them can develop vocabulary and language use for face-to-face communication;

- demonstrate how to provide access to print and interaction during print-related activities for persons with severe speech and physical impairments by using all their modes of communicating.

There is a plethora of definitions of language in our culturally diverse society and we must consider all types of linguistic codes and their unique components in teaching persons. Perhaps Minspeak™ does not fit the definition of a language in the strictist sense of linguistic theory. This system is a viable way of communicating used by thousands of non-speaking people. Minspeak™ is *one* of many tools for communicating and for developing an understanding and use of language. AAC users can understand, read, write, and speak if someone will teach them.

How to best use AAC communicators' systems and abilities to develop competence in all aspects of their native written and spoken language? That to us is the most important question, one which we must try and answer together. §

Some Notes on Minspeak™, Language, and Language Development

ERIC NYBERG, 3rd



Eric Nyberg is a member of the research faculty in the School of Computer Science at Carnegie Mellon University. His research interests include computational models of early language development, and language translation software systems.

In the previous issue of **Communicating Together**, Shirley McNaughton and Margareta Jennische raised several points concerning the definition of language, the symbol sets used in communication aids, and the role that these potentially play in language development. In particular, several questions were raised concerning the status of Minspeak™ and its influence on language development.

The first issue centers around the definition of the word “language,” and the question of whether this term is appropriately applied to the symbol systems used in AAC devices. As pointed out by Shirley McNaughton, the definition of “language” taken from Rees (1980) emphasizes the computational nature of language, namely, that it is a “code with struc-

tured properties, characterized by a set of rules for producing and characterizing utterances.” Although human language fits this definition, there is much more to language — we must also consider how language fits into the complete set of cognitive skills that a person possesses. Language cannot be separated from the process of language development. Language development involves not only learning the “rules” of language but also the entire set of skills related to knowledge of the world (the objects, activities, and relationships around us) and the other aspects of communication (principles of social interaction, conversation, etc.). It is argued that “approaching language as a code, although it serves to describe its form, does not provide the kind of information we need in order to understand the

many domains of language developing within the individual."

It is clear, then, that there are two ways to describe a language. One may describe the properties of the language itself, or its "rules," and one may also describe how a language is learned and how the development of that language fits into the overall development of cognitive skills. The first kind of description is very helpful when we wish to analyze the computational properties of a language, perhaps in hopes of providing a communication aid using a particular symbol set; the second kind of description is important when we wish to verify that a particular symbol set and how it is taught to children fits well within the normal course of cognitive development. The overall concern expressed by both Shirley and Margareta is that the Minspeak™ paradigm focuses on the "code approach" to language, and that by implication Minspeak™ is somehow lacking in how it fits into the normal course of cognitive development. In the remainder of this article, I will show that quite the opposite is the case. Let us consider the points raised by Margareta Jennische.

The first concern raised by Margareta is whether Minspeak™ is an appropriate communication paradigm for children during the formative stages of language. There seems to be an expressed consensus that Minspeak™ can be an appropriate tool for non-speaking adults, but that there are serious implications when Minspeak™ is used with young children. There are two important points which are worth mentioning here. The first is that Minspeak™ itself is primarily a way of linking icons, and that this technique has been applied for several different groups of users through specific Minspeak™ Application Programs; e.g., WordsStrategy; Interaction, Education and Play (IEP); Power in Play (PIP+); etc. These Minspeak™ Application

Programs (MAPs) all make use of the same iconic technique (semantic compaction), but use associations that are of appropriate complexity for the users in question.

The second point is that Minspeak™ applications should of course be provided with a comprehensive teaching strategy that is appropriate for the cognitive abilities and life experiences of the user in question. Each set of icon associations fits within a complete teaching paradigm that is not only accessible to the child, but also helps to enrich the development of his or her cognitive skills and interactive capabilities. For example, Power in Play (PIP+) uses a drawing of a piano to encode the concepts of "music," "sing," and "loud." As part of the teaching strategy, the facilitator and child might pick out music together, bang loudly on a piano, and sing together. When using Minspeak™ with children, the emphasis is appropriately placed on teaching language through life experiences. The associations used in Minspeak™ emphasize the characteristics of objects and the relationships among objects in a way that makes it easy to create training materials that enumerate many characteristics and many relationships for the child in a stimulating learning environment.

During the past several years, as Minspeak™ has been incorporated into communication aids for young children, a large body of clinical research has focused on the issue of how to select icons, associations between icons, and teaching strategies that support language development. For example, Bruno (1989) explored the customization of a Minspeak™ system for a pre-literate child, and demonstrated that selecting a symbol set that is appropriate for the cognitive and receptive language abilities of the child leads to success in use of the communication system. At least one large comprehensive clinical study has been specifically focused on the

Minspeak™ paradigm. Carol Goossens, Pam Elder and Norman Bray (Goossens et al., 1990) defined a set of cognitive skill levels which have a strong correlation with the use of icons and icon associations; a competency profile which tests these skills indicates which kinds of icons and icon sequences are appropriate for a given child based on their developing skill set.

Margareta cites a case where "the face of a man is used to represent *pants*," with a concern that an inappropriate conceptual framework is implied by this type of association. The reason that this example might seem problematic is that it is taken outside the context of the teaching paradigm that is used to instruct the child in the use of the association. In the initial version of IEP, direct visual representation of "pants" and "dress" were not chosen because these items of clothing appear in icons where they might be difficult for the child to locate visually. Instead, answers to the simple questions "What does Mommy wear?" and "What does Daddy wear?" were used to teach the child the icon sequences CLOTHING + WOMAN = "dress" and CLOTHING + MAN = "pants." Taken in context, these associations are quite evident and easy for the child to internalize. It is important to keep in mind that a successful choice of icon sequence depends on both the icons themselves and the teaching paradigm used with a particular age group.

The crucial distinction underlying this discussion is that Minspeak™ is not a single set of icons and associations, but a technique that can be used to develop many different sets of icons and associations which are appropriate to particular groups of users. It should also be clear that the Minspeak™ research community has invested a significant amount of research and development in building systems which are appropriate for young children; interested readers need only read through the Minspeak™ Confer-

The second concern voiced by Margareta Jennische is whether it is appropriate to call Minspeak a "language." Properly speaking, Minspeak™ is not a language, nor have its proponents claimed that it is a language. Rather, Minspeak™ is a way of organizing symbols so that they can be joined together to access a vocabulary with a minimum of keystrokes. Access to a very large vocabulary of words and phrases can be achieved with only 2 or 3 keystrokes per item, a significant improvement over word prediction systems or spelling-based systems. This is achieved through the use of a single overlay containing icons, without requiring that the user navigate through a series of separate menus or overlays. Since Minspeak™ systems incorporate a speech output device, non-speaking children can communicate with their non-disabled peers and thus gain valuable interaction which stimulates normal language development. Because the icons and icon sequences that are chosen for particular applications are easy for children to understand and remember, the mnemonic ease of using Minspeak™ is excellent. When coupled with the low number of keystrokes required for vocabulary access, the ease of remembering Minspeak™ sequences provides a very powerful communication tool that facilitates communication rates which support interactive conversation.

As pointed out by Shirley McNaughton, the use of the term "language" can be tricky, since it means many different things to different people; but if we take the definition of language to be as Shirley suggests, namely, a "set of interrelated component or domain competencies" spanning the range of morphology, phonology, syntax, speech acts, conversation, discourse, etc., then we see that although Minspeak™ effectively represents the semantic and surface structures of language, it does

not attempt exhaustively to characterize them in a way that would make Minspeak™ a language in the sense that English is a language. Of course, since Minspeak™ is intended to be a practical aid for communication, its theoretical status as a "language" is a topic only for intellectual debate.

The third concern raised by Jennische is whether Minspeak™ has a questionable influence on the development of conceptual structure in the young child. As noted previously, there is a body of clinical research in this area which suggests that Minspeak™ icons and associations, if chosen appropriately for the particular child's cognitive skill set, can stimulate the development of the conceptual structure by elaborating the set of characteristics of objects and relationships among objects. Minspeak™ does not attempt to replace the child's developing language competency with a language model of its own. It is worth pointing out that the ultimate goal of providing a young child with a Minspeak™ system is to stimulate development of his or her own native language competence by providing access to communication and interaction with others.

The final issue raised by Margareta concerns the usefulness of the Minspeak™ icon sequences in the absence of a voice output generator (for example, when there is a power failure). The point is that the other participants in a conversation would not be able to interpret the icons themselves and that effective communication would be impossible.

It is worth pointing out that this problem arises with any symbolic encoding technique, not just with Minspeak™. Regardless of the symbols used, if there is no voice output there will be no communication unless the communication partner has also learned the symbolic encoding technique well enough to interpret the symbol sequences in the absence of voice output. This is true of Bliss,

Minspeak™, etc. A competent clinician will always ensure that a backup system is available for the user. It is also worthwhile to note that Minspeak™ has an advantage in that it supports interaction with non-disabled peers without requiring that they master the system. This is in contrast to systems which lack voice output and require that all parties in the communication understand the symbol set and production/comprehension rules.

In a field where theories of language and cognition overlap with the practical concerns of providing access to communication, it is easy to mix up theoretical claims about "language" with judgements about the usefulness of a particular paradigm for practical communication. I agree with Shirley that it is very important to consider the full range of characteristics that language has, especially with an eye towards language development. It is also important to look beyond the "code approach" to communication aids and also consider the teaching strategies used and how they fit in with the cognitive development of the child. It has been my experience that the Minspeak™ community has been quite concerned with the theoretical status of Minspeak™ as a tool that supports the development and use of language. Success in facilitating practical communication involves a lot of clinical research and development and a clear understanding of the cognitive processes of children. It is my opinion that the Minspeak™ paradigm has developed in specialized ways for younger children that is cognitively appropriate as well as practically successful.

There is a danger when intellectual debate about one "theory" versus another overshadows what should be our primary concern: providing communication for our user community. I have tried to show how the Minspeak™ developers have carefully considered the issues raised by Shirley

nity. I have tried to show how the Minspeak™ developers have carefully considered the issues raised by Shirley and Margareta. In this context, it might be important to note that Bruce Baker, the creator of Minspeak™, has never described Minspeak™ itself as a "language," but as a tool to enable people with disabilities to use the natural language of their environment. Although none of us would claim that Minspeak™ is a language like English,

Minspeak™ has undergone a great deal of analysis in conjunction with clinical research focused on children. Although it is useful to consider all of language when building a communication aid, in order to ensure that the communication aid does not interfere with normal language development, it should be clear that the ultimate goal of AAC is building useful communication aids, and not developing an abstract theory of language.

§

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READERS WRITE

Dear Editor:

I read with interest your recent issue of **Communicating Together**, with its special focus on Facilitated Communication with autism. There can be no doubt that this approach to communication has rivetted the attention of professionals and parents who continue to look for ways to help individuals with autism get access to communication. Since we at The Geneva Centre have become aware of FC, we have been wrestling with the myriad of new questions it generates and the shortage of answers to be found.

As it happens with any new and challenging idea, we have all witnessed a polarization in the reactions to FC. Some seem to be blindly exuberant in their belief in this technique. Others seem to experience an abhorrence to the notion of yet another claim of false hope. Your issue of **Communicating Together** provided a much needed opportunity to identify the middle ground. Regardless of our excitement or skepticism about FC, we all need to be reminded to maintain a view of the bigger picture of autism. Putting FC in a perspective which identifies it as one of many tools for communication which may be helpful to individuals with autism is a respectable response to the many unknowns about FC. It will likely be a number of years before there is sufficient empirical evidence to guide us in understanding the full implications of this technique.

There can be no denying that FC has had a profound impact on the field of autism, and on individuals with autism and their families. The dramatic shift in attitude toward individuals with autism has thrust forward the efforts to normalize their life experiences. Even talking to individuals with autism in a way which implies more competence than previously thought is a dignifying experience.

The Geneva Centre is committed to providing a broad range of current information on autism to anyone with such an interest. To this end, we have undertaken to gather all published information about FC, both pro and con and to make it available for the asking. In our own intervention with children with autism, we include FC as one of the options available when assessing communication. In our training programs, we provide a thorough overview of autism and the questions generated by FC and a demonstration of the technique. All participants in our FC training are encouraged to try it if and when they are comfortable, and are encouraged to call us after trying it for support, more information if necessary or to receive additional demonstration.

Sincerely,

Margaret Whelan
Executive Director
The Geneva Centre
Toronto, Canada

READERS WRITE

Dear Editor:

Thank you for your recent issue on Facilitated Communication. I found the issue presented questions on both sides of the coin with which I have been struggling for the past year since I introduced FC to some of my clients. Instead of following the train analogy, however, our experience has been one of a roller coaster ride - from the initial exhilaration of the first hill to all the many dips and turns which take place adding some excitement, to the end of the ride with small fluctuations as the roller coaster glides into the place where you started. Does this mean we are not enriched by our experience? On the contrary, my department and I have found that we, as well as our clients, have experienced the thrill of the ride, and we regularly experience the ride over and again as we introduce new aspects to their communication development. The station we seem to return to, however, is: What are the long range implications for the client's *overall* development? Observations which return us to this question are as follows:

1. Clients do not respond to the same extent with each facilitator. We have clients who may spell paragraphs with certain facilitators and extend down through a range of responding to yes and no questions or identifying picture symbols with others. If a communication system is to be flexible and useful enough to be used across contexts, the intra-client variability observed may be too great to make spelling with FC a viable method for all the client's needs, but may be useful for certain interactors in certain contexts only, and other systems cannot be abandoned.
2. Certain clients have not demonstrated the oft reported decrease in less desirable behaviors, but rather the intensity of behaviors have escalated or behaviors have become even less acceptable. Such behavior changes seem to be associated with expressions of frustration with the lack of life change experienced by the client. We cannot choose to ignore these client's desires of change, yet we also find ourselves dealing with service systems not yet entirely ready to change, and which become more rigid as the external behavior observed becomes more difficult to deal with.
3. Though literacy skills have been uncovered, with concurrent increase in perception of cognitive skills extant, the social-emotional content of messages would suggest persistent delays in this area of development.

May I add two additional comments. First, the way FC is presented to the population at large seems to have created a confused understanding of what FC is and is not. FC is merely a technique within the realm of AAC and to speak of it as an entity in and of itself grants it a life beyond itself; where FC takes on the exclusivity of spelling with a Canon Communicator only. To alleviate this problem, when communicating with parents or other personnel about our program suggestions I have taken to speaking in terms of the "Facilitated Method" or the "principles of Facilitation."

Second, I have begun to wonder if Donna Williams' observations about her experience of dissociation or compartmentalization of her communication may have some implications with some clients' unexplained literacy or why those skills have remained latent to this point. As evidence for this, may I point out her statement in the Gzowski interview to the effect that she typed the book manuscript without thought. Also, one client of mine seems to disassociate his facilitated thoughts from himself as an entire individual. Another refers to himself as being more than one person, and we may be communicating with only one of those "entities."

Certainly FC presents fodder for some interesting, exhilarating discussion at this juncture. May I close by suggesting that as part of your journal you include a regular column on this phenomenon as a regular forum for discussion of the issues FC presents us.

Thank you.

D. MacKenzie, B.SC.(C.D.) Reg. O.S.L.A.
Senior Speech Pathologist
Cochrane Temiskaming Resource Centre.

CONTENTS

2	EDITORIAL	PETER LINDSAY SHIRLEY MCNAUGHTON
3	FEATURE ARTICLE On Being Sarah	ELIZABETH HELFMAN
5	LIVING Relationships with Attendants	KARI & RUTH HARRINGTON
7	CONSUMING TECHNOLOGY Measuring Interface Device Performance	JENNIFER ANGELO
9	TEACHING AND LEARNING Keyboarding Instruction Correspondence: "Let Your Fingers do the Talking"	CATHY VITEZ
12	CONTEXTS Reviews and Plugs	GEB VERBURG
14	PERSPECTIVES Facilitated Communication: Some Further Thoughts	ROSEMARY CROSSLEY
17	PAUL'S PLACE The Culture Barricade	PAUL MARSHALL
18	SYMBOL TALK Linking Symbols with Language	SHIRLEY MCNAUGHTON NORTH CAROLINA LITERACY CENTER
19	Minspeak, Language and Language Development	ERIC NYBERG, 3rd
22	READER'S WRITE	MARGARET WHELAN D. MACKENZIE

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